STRATEGIES AND CHALLENGES IN SUPPORTING CHILDREN WITH COMPLEX MEDICAL NEEDS IN THE COMMUNITY: REPORT ON A SITE VISIT TO WESTERN PENNSYLVANIA

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The Call

In early 2000, the Center on Human Policy started to receive reports that children with complex medical needs were being placed in nursing homes because of home care nursing shortages. As we explored the issue locally, it seemed that framing the issue as a nursing shortage directed solutions that revolved around nursing agency staff recruitment and retention strategies. We wondered about what solutions would be sought if the problem was framed as a permanency issue. Permanency gives primacy to the relationships in a child's life. Permanency is about filling relational needs. Nursing shortages is about filling shifts. We wanted to explore some different perspectives, so from the Center on Human Policy we put out a call asking for recommendations of places that, on a routine basis, were effectively supporting families with children who have complex medical needs. This report reflects the response to that call and identifies some of our thinking about the issues raised in that response.

National Context

Since the late 1980s, there has been widespread agreement with the philosophy that "all children belong in families," and that families should be supported to keep their children at home. The Center on Human Policy published "A Statement in Support of Families and Their Children" in 1987 that received widespread endorsement and support from individuals and organizations, and was, in some states, incorporated into family support legislation.

The belief in families for all children has come to be addressed under the rubric of "permanency." Philosophically, permanency is based on the belief that all children belong in families. Permanency recognizes that children need an enduring relationship with at least one adult on a daily and ongoing basis for growth and development. In practice,

permanency involves supporting birth families with "whatever it takes" to enable them to raise their children, and finding temporary foster families (as a transition during reunification or permanency planning) or permanent adoptive families when children cannot remain with their birth families.

In the Spring of 2000 we were still searching for ways to support children with significant health and disability needs. The success of living in family homes is directly related to the effectiveness of supports to families. In the Spring of 2000, we at the Center on Human Policy were still searching for concrete examples of successful support strategies for children with the most significant health needs.

In practice, in the past 20 years, there has been a significant increase in the number of children who live at home with their families with supports, including children with severe and multiple disabilities. More family support services are based on principles of individualized, flexible supports; based on the family's and child's needs; and based on the strategy of providing "whatever it takes" to support children and their families. In many states, there has been a dramatic decrease in the number of children who are admitted to institutional or nursing home care. Funding, staff, and equipment formerly used to care for children in facilities have been redirected to support families at home.

At the same time, despite widespread articulation of the value of children belonging in families, there are still some children who are slipping through the cracks-ending up in residential facilities ranging from small and large group homes to nursing homes. Often, these are children with complex medical needs. Even though there are special programs (that support children to live with their families) in various locations around the country that have demonstrated the efficacy of providing home care for children with complex medical needs, these programs are often available only for a limited number of children, or only available for a narrowly defined group of children (e.g., children who use ventilators). We wanted to learn more about the success and challenges of effectively supporting families with children who have complex medical needs, so we put out a call asking for nominations of places where this happened on a routine basis.

Response to the Call

Interestingly, we did not receive nominations of any strongholds of successful practice. Rather, we heard from many people requesting us to share information about any successful places that we did find. We heard about places that were trying, with mixed success, to implement the philosophy. In particular, we heard of efforts being made in western Pennsylvania to better support children with complex medical needs in families and to reunite birth families or find new families for children who had been placed in facilities. This effort was underpinned by a class action lawsuit (Cordero v. Commonwealth of Pennsylvania) that resulted in a settlement mandating examination of the system challenges in supporting children with disabilities in integrated settings. We decided to conduct a site visit to the Pittsburgh area to document both the positive efforts being made as well as the continuing challenges to serving these children and their

families. This report is based on information obtained during that visit in June 2000, and does not address any changes that may have occurred since that time.

We commend the individuals and organizations in western Pennsylvania for opening themselves to this public scrutiny. We met with children and adults with disabilities, parents, foster families, service providers, and advocates. Their willingness to expose their limitations as well as their strengths is testimony to their commitment to struggle with difficult issues. These limitations are not unique to western Pennsylvania, but face all states and localities as they wrestle with truly effective family supports within real-world constraints.

We begin with a description of some of the positive efforts that have been made in western Pennsylvania toward supporting all children in families. Next, we present the experiences of three young people and their families in order to illustrate both positive efforts and significant challenges. Finally, we summarize some of the strengths and challenges.

Family Supports in Western Pennsylvania

Pennsylvania is a state that is recognized for many individuals and organizations that are strong advocates for people with developmental disabilities and for examples of innovative, individualized supports to people with developmental disabilities and their families. Some of the statewide and regional initiatives related to children are described below.

Permanency planning. For a number of years, Every Child, Inc. (formerly Permanency Planning Services, Inc.) has directed efforts in support of children with severe disabilities based upon a permanency planning philosophy and practice. This has included supporting birth families, as well as finding and supporting adoptive and foster families. Every Child, Inc. has demonstrated the implementation of these practices for children who have significant medical challenges.

Respite coalition. A respite coalition was formed in Allegheny County, the metropolitan area of western Pennsylvania containing the city of Pittsburgh and its suburbs, in response to families' needs for and difficulties in obtaining respite. This is a coalition composed of family members, service providers, and policy makers. The objective of the coalition is to address, in a comprehensive way, respite for children across disability, including those with complex health care needs.

Statewide Adoption Network. The network provides a mechanism to track every child who is available for adoption and pool available potential adoptive families in order to maximize the possibility of a successful match. Children with special needs are eligible for an adoption subsidy.

Ventilator Assisted Care Program. This program started in 1979 and focuses on helping children 0-21 who use mechanical ventilation and live at home. The program coordinates

medical and support needs by helping to fund in-home support and respite services and providing specialized case management for families. The program was started in Philadelphia and later expanded to western Pennsylvania. Currently, the western Pennsylvania office supports approximately 65 children and their families.

Legal advocacy. The Disabilities Law Project provides support to individual parents in the pursuit of services for their children. In addition, the Project is involved in state-level advocacy efforts to expand services, in particular through Medicaid waivers.

The Watson Institute (formerly D.T. Watson Rehabilitation Hospital). This is an adult and pediatric rehabilitation facility in western Pennsylvania which also offers numerous community programs. The Watson Institute played an integral part in assisting children with complex medical needs to pursue permanency by returning them to Pennsylvania from out-of-state adult nursing homes and providing them a transition residence and care in the inpatient rehabilitation hospital.

Center for Creative Play. Started in 1995 by five mothers who have children with disabilities, the Center for Creative Play is a place where all children (including those with and without disabilities) can come to play. In addition to providing a play space, the Center offers concerts, cultural activities, toy lending, a summer creative arts camp, respite for parents of children with disabilities, and parent networks regarding disability issues.

In spite of these efforts combined, some children, particularly those with complex medical needs, have fallen through the cracks in the system and have been placed in nursing homes and other residential facilities. For some of these children living in residential facilities, educational and community services have proven difficult to secure. For some children, lack of available services within the state has led to placement in out-of-state facilities. As part of a settlement agreement in the Cordero case, an interagency committee was created to coordinate efforts to promote policy and practice changes. The Cordero Committee is made up of parents, service providers, advocates, and state and local officials. The committee is charged with looking at the broad issues affecting children with complex medical needs.

At the time of our visit, the committee had taken a number of steps to identify children and families, and to delineate the issues and barriers to adequate services. These activities included: a survey to identify children living in settings other than family homes; efforts to ensure that this group of children is included in statewide planning initiatives; efforts to obtain increased waiver funding for these children and their families; and specific efforts targeted at bringing two teenagers home to their community of Pittsburgh from out-of-state nursing homes.

The committee's choice to devote significant energy to these two children represented both a commitment to these teens as well as an opportunity to explore the barriers and potential solutions at the ground level with an eye to supplementing the committee's efforts at a statewide level. While the committee's efforts have brought more awareness

of the issues and promoted various system changes, the specific barriers encountered in efforts to bring these young people back to their community highlight many of the remaining challenges within the system.

In the following section, we profile some of the experiences of three young people and their families--Denise, Stuart, and Trisha--based upon interviews with the young people themselves and/or family members, as well as interviews with others who were involved with helping to plan for community services for Denise and Stuart. Denise and Stuart are the two young people who have been the focus of the Cordero Committee's efforts, and Trisha, who lives with her family, was one of the first children with complex medical needs in the state to receive in-home supports.

Denise

Denise turned 14 years old in the Spring of 2000. When Denise was 8 years old she was transferred from a pediatric hospital in western Pennsylvania, where she had been receiving care for an acute illness related to her complex medical needs, to a nursing home several hours away in Ohio. The placement occurred because Denise was deemed too medically involved for the pediatric residential facilities in Pennsylvania, and professionals considered her single parent as an inadequate caregiver because of his limited support network and his own chronic health condition (diabetes). Denise remained in Ohio for several years. When members of the Cordero Committee initiated their efforts to bring young people home from out-of-state nursing homes, Denise was one of two people identified as part of this effort. A permanency planning team working in collaboration with The Watson Institute and the Cordero Committee returned Denise to western Pennsylvania.

Denise lived at The Watson Institute while a family-centered futures plan was facilitated to determine how to provide permanency for Denise. During the futures planning process, it was very clear that Denise's father Edward was anxious to have his daughter move back home with him. The effort to bring Denise home took 9 months of planning that involved family members, representatives from the rehabilitation facility, community members, and nursing agency personnel. The planning focused on finding Edward an affordable single-story accessible home that could support all of Denise's equipment, identifying in-home support staff, coordinating a school placement, and supporting Edward to receive training to provide Denise's medical care. The futures planning team worked collaboratively with the managed care company that was developing a health care plan to transition and support Denise in her home. An assessment by the managed care company indicated that Denise would need 24-hour a day nursing, at least to begin with. According to some of the people who were present at these meetings, the nursing agency chosen to provide care agreed to provide this 24-hour nursing. In addition, the nursing agency agreed to take responsibility for arranging delivery of Denise's prescriptions and medical supplies.

On February 15, 2000, Denise moved home with her father to a two-bedroom single-floor apartment. Due to the space taken up by her medical equipment and supplies, the living

room became Denise's bedroom. For the first 3 days that Denise was home, she received 24-hour nursing. However, since that time, although she is still supposed to be receiving 24-hour nursing, the shifts have been not been filled, and Edward has provided an average of 8-16 hours and sometimes 24 hours of medical and personal care for his daughter, in addition to his full-time job. Sometimes there is little if any advance notice when a nurse does not show up. Edward's employment has been jeopardized because of the number of times he has been late or has called off as a result of the lack of nurses. All of his vacation time and sick time has been depleted. Denise also has missed school frequently when the nurse does do not show up and she is not ready in time for the school van or when the nurse assigned to school calls off, requiring her father to take the day off to stay at home with her. In addition to the personal care for his daughter, Edward has spent time waiting in line at stores to order and pick up her prescriptions and medical supplies, which are not being handled by the nursing agency.

Overall, Edward is thankful to have his daughter with him, but because of the many problems they have had with services, Edward does not feel supported; instead he talks about how the system has been destructive to his life-"It's not a service; it's a disaster." According to Edward, the nursing agencies have not offered any backup assistance when nurses fail to show up. Second, Edward is concerned that some of the nurses who have come do not have adequate training for the care of Denise (e.g., some of the nurses who have come are not familiar with use of some of the equipment required by Denise, even basic equipment such as a hoyer lift). Finally, he is frustrated by the lack of assistance provided by case management to help him work to resolve these issues with the nursing agencies and find back-up support when nurses do not come. The high stress for Edward that is involved in compensating for lack of support has posed a threat to his health. However, his primary criticism is the negative effect on Denise.

At first, when Denise came home, Edward foresaw finally an opportunity to be a family and do enjoyable things with his daughter at home and in the community. For instance, when she first came home, they were able to attend a community event at the nearby Civic Arena. However, due to lack of nursing support and accessible transportation, they have not been out into the community since that time. Altogether, he feels that the lack of supports has "taken away my ability to help her have a life."

Stuart

Stuart, like Denise, lived in a nursing home in Ohio until recently, when he became the focus of efforts by the Cordero Committee to assist young people to move from nursing homes back to the community. Committee members helped pull together a circle of support to plan for Stuart's return. Rather than remaining in Ohio at the nursing home during the course of planning and preparation, Stuart also moved into The Watson Institute rehabilitation facility in suburban Pittsburgh. Stuart made clear that his ultimate intention was to move into a family home in the community, despite the protests of his parents, who felt unable to care for him themselves. Stuart's father and stepmother, who had at one time been Stuart's nurse, felt that they were not getting enough support and services to keep Stuart at home in light of his degenerative disease. Despite their

concerns, Stuart continued to hold on to his vision of living with a family, and it was also the intention of representatives of the Cordero Committee and at least some other members of Stuart's circle of support that they would assist him in pursing this.

However, planning for Stuart's move from the rehabilitation facility into a home in the community became a long and frustrating experience for Stuart and some of his support circle members. One of the major impediments was the lack of definite funding for Stuart after the age of 21. Throughout Pennsylvania, there are a variety of state and Medicaid waiver funding options for children with severe disabilities and/or complex medical needs. However, once a person reaches the age of 21, the funding for community supports is much more difficult to obtain.

At one point, frustrated with the process, Stuart contacted a newspaper reporter, who wrote a story about Stuart's desire to live with a family. In response, a number of families expressed interest in the possibility of having Stuart live with them; however, when they found out about the possibility of loss of funding when he turned 21, they were hesitant to move forward. During the course of our interviews, we heard one person recall that "no families were willing the take Stuart." It was clear, however, that a number of families were potentially willing to have Stuart live with them, but that they were not offered assurance of support after Stuart turned 21. While living at the rehabilitation facility, Stuart attended the local public high school. His classmates there heard about his desire to live in a home and his difficulty in doing so; considering this, they began organizing and fundraising in an attempt to assist him.

Also, during the long, drawn-out process of assisting Stuart to move, the membership of his circle changed and, over time, came to be composed primarily of staff from the facility. Most of these staff continued to participate in Stuart's planning meetings, on their own time, out of their genuine concern for Stuart and his uncertain future. At the time of our visit, the rehabilitation hospital, which had previously operated as a nonprofit, was sold to a for-profit company and converted to an adult rehabilitation facility that no longer accepted pediatric residents. As a result, there was a new source of pressure for Stuart to move. However, there was still need for funding for Stuart after age 21. Staff at the facility contacted a legislator, who obtained a special appropriation guaranteeing funding to support Stuart. However, the funding was targeted toward a group home, rather than to a family. While it appeared, initially, with his move back to Pittsburgh from Ohio, that Stuart was closer to realizing his dream of life with a family in the community, it seemed, at the time of our visit, that the realization of that dream might not happen at all, even though a special appropriation was obtained and a number of families were potentially willing to have Stuart live with them.

Trisha

Trisha, who is now 20, was, as a child, one of the first with complex medical needs to come home from the hospital and live at home with her family with support. At that point, she had a tracheostomy and used oxygen. About every 8 weeks, she would end up back in the hospital. At that time, schools were not required to accept children with

disabilities, so she did not receive any early intervention services. According to her mother, she was turned away by all of the local educational and rehabilitation facilities specializing in services for children with disabilities. As Trisha's mother described,

> Finally, the public school said they would let her come. That's when we began to use more nursing, because we sent nurses to school with her. We hired our own nurses. I would hire them, and I would pay them, and submit the reimbursement to the insurance company. They were OK with that up til that time. But then they said, we can't reimburse you for nurses you pay yourself. You have to use an agency. It's very frustrating having to go through the agencies because you loose so much control. It's been hard, at times, trying to find people who are skilled-as well as people who understand your values and what you're trying to accomplish.

When Trisha was placed on a ventilator, they had to rely more on nursing care. They met to plan with home care representatives. However, her mother, Margaret, describes the subsequent difficulties in implementing those plans:

> What the nursing agencies guaranteed us, at least initially, was this whole cadre of professionals, so if somebody calls off, we'll always have somebody else. And they've never been able to deliver on that.

Margaret explained after one hospitalization the insurance company agreed to give them 16 hours of nursing a day, but then after Trisha was home only a little more than a month, the insurance company started calling to suggest that it was time to cut the nursing hours back. She said they had pressure to reduce hours on a regular basis.

Margaret explained that the challenge now is that Trisha is being funded by the EPSDT (Early Periodic Screening, Diagnosis, and Treatment) program, but that children are only eligible for this until they turn 21. In addition, the Ventilator Assisted Program at Children's Hospital only goes up to age 21. They are currently checking to see about qualifying for a Medicaid waiver; however, in order to qualify, you must have exhausted your private insurance. Reflecting on one of the major problems that she feels is at the root of her difficulty in finding supports within the system for her daughter, Margaret commented, "Kids like my daughter didn't used to live very long, so there's no plan for what to do beyond 21."

Trisha has been taking courses at Duquesne University. There are many college students who are involved in supporting her and who have become friends. However, it has been Margaret who has been responsible for the work of coordinating this support. Also, as Trisha is becoming a young adult, her family would like her to be able to explore different living options, such as apartment living, if she is interested. However, at this point, Margaret explained "the only way I can maintain health coverage for her at this point is for her to stay in our home."

The experiences of these young people and families illustrate both some of the strategies that promote family life for children with severe disabilities and complex medical needs as well as some of the challenges related to supporting all children to live in the community. These strategies and challenges are discussed below.

Strategies and Challenges in Supporting All Children in Families

This section highlights some of the strategies used by individuals and organizations that are key to successfully supporting all children in families.

1. Recognition of the importance of relationships and work to support relationships. It is of primary importance that those who are working to promote homes for all children in the Pittsburgh area are doing so based upon a value and recognition of the importance of relationships. First, they have worked based on the assumption that all children need loving, enduring family relationships; thus, they have directed their efforts to supporting and reuniting families, as well as to creating alternative families. Second, they have recognized that relationships between families and service providers (e.g., in-home nurses, case managers, other agency staff) are critical; thus, they have worked at establishing positive, trusting relationships with families, and have advocated for and with families around service and support issues. Finally, they believe that it is important for children to have the opportunity to engage in relationships with others in their community in addition to family and service providers. Thus, they work to create and support such opportunities--for example, Trisha's participation in social life at college; Stuart's relationships with peers at his neighborhood school; that the Center for Creative Play offers an accessible, fun setting for children with and without disabilities; and that Denise's father has time to relax and have fun together with her, rather than just caretaking interactions.

2. Commitment to permanency planning. The commitment to permanency planning, by Every Child, Inc., as well as some others who are working within the system, has been key to enabling many children with severe disabilities, including some with complex medical needs, to live with families. As part of permanency planning, they have incorporated a broad variety of supports for families, including: person-centered planning around the child and his or her family, individualized and flexible supports for the child and family, information and assistance in obtaining resources, open lines of communication, assistance with service coordination, and advocacy for and with families with regard to service system issues. In addition, this emphasis on permanency planning has included devoting resources and energy toward recruiting and supporting adoptive and foster families for children who cannot remain with their birth families.

3. Coalition building. An important strategy used by those who are promoting inclusion for all children is building coalitions composed of parents, service providers, policy makers, and others. They have formed coalitions in response to identified needs (e.g., the Allegheny County Respite Coalition's efforts to create legislative and community awareness and funding sources to promote accessible, affordable, quality respite care; the Statewide Adoption Network; the Cordero Committee), and they have used these coalitions for educational purposes, to identify key systems shortcomings or barriers, and to advocate in relation to these issues.

Following are some of the challenges to inclusion for all children.

1. Across the system, beliefs must be extended beyond philosophy to practice by fully embracing permanency principles. There is widespread agreement with the idea that all children should live in families, and support is provided for many children to live with families (birth, adoptive, and foster). While articulating this stance, the depth of understanding and commitment to the belief is exposed as more rhetoric by many than practice. Sorting out the contributing factors to the discrepancy between philosophy and practice is at the crux of the issues facing children with complex needs. There are three areas where the stated commitment to the belief is inconsistent with its actual implementation: (a) interpretations of family "choice," (b) expanding facility options, and (c) facility admissions pathways.

People at all levels of the system (e.g., administrators, case managers, providers, etc.) found no discrepancy between stating that children should grow up in families and then participating in a decision to place a child in a nonfamily residential facility. Sometimes the decision was justified on grounds of inadequate resources to support families, without recognition of the resources required to support the residential facility. Sometimes the decision was justified on the grounds that there were no other options, without recognition of potential foster or adoptive family options. Sometimes the decision was justified on the grounds of family choice, without recognition that the "choice" was a default position caused by resources tied to facilities rather than families or inadequate alternate family recruitment efforts. Sometimes the decision was justified on the grounds that parental preference should direct the decision, without recognition of the conflict with a child's best interest. One worker explained it this way: "I think it is most important to listen to the family. If the family wants an ICF/MR, then it's my job to guide them to an ICF/MR." An administrator explained, "Birth families don't want their children with another family." When confronted, the administrator admitted, "We ended up going with the family's wishes." The default policy is that parental preference overrides the belief that children should grow up in a family.

In western Pennsylvania, and across the country, there is a small but alarming increase in facility expansion. Implementing permanency entails not only rhetorical commitment to more and better support to families; it requires redirecting resources from nonfamily residential options and aggressive alternate family recruitment. The elimination of the option of placement in a facility requires control of the pathways by which children end up in facilities and controlling the decision-making process that approves nonfamily options. The approval of facility entry is not currently driven by permanency policy but rather is driven by availability. Neither case managers, ICF/MR facility representatives, nor managed care providers should be in a position to approve placement in a facility. The gate to facility admission needs to be tied to permanency plans, to authority to approve alternatives, and to the responsibility to develop alternatives. To move beyond philosophy to practice, there needs to be a more specific strategy to redirect resources from facilities, greater investment in alternate family recruitment, and tighter control of facility admission pathways.

2. Managed care is out-of-synch with permanency planning. The difficulties surrounding children with complex medical needs are exacerbated by the managed care environment. Managed care, as currently implemented, poses a significant threat to family-based care for children with expensive support needs. Managed care is primarily a cost control mechanism. The concept of permanency and its rationale is not (yet) part of the managed care ideology. If a child can be supported more cheaply in a facility than a family, managed care will approve the facility option. Management that focuses on resource expenditures rather than permanency outcomes will approve plans that are inconsistent with permanency. An example came from a meeting regarding the planning for one of the teens who moved back to Pittsburgh from the out-of-state nursing home. A representative of the managed care organization is reported to have stated that "She belongs in a facility." With decision-making delegated to managed care organizations fueled by this kind of attitude, the climate is ripe for a resurgence of residential care for children. An advocate described managed care as "the family being managed in a way that doesn't support the family." An administrator declared, "The tail is wagging the dog." In the absence of a real commitment to permanency, medical care facilities are likely to grow. A real commitment to permanency will recognize that home care is a priority over facility care even if it costs more. A true accounting of the benefit side of cost/benefit analysis will take into consideration the benefit of family life as offsetting any cost savings of facility placement.

The challenges of managed care are not unique to Pennsylvania. The U.S. General Accounting Office (GAO) (2000) is calling for specific guidelines for managed care for children with special needs. There is a need for a coordinated, strategic response by states and localities together to the challenges posed by managed care (American Network of Community Options and Resources, 1997; Center for Children with Chronic Illness and Disability, 1997).

3. The intent of services is compromised by some of the rules, regulations, and practices created to govern their implementation. Currently, the system of support services does not feel very supportive to families of children with complex medical needs. In some cases it is doing damage to families. Well-intended staff, working in ways that are consistent with permanency and congruent with families' desire to care for their child at home, are hampered by rules and regulations and practices that are counterproductive to that end, but are also counterproductive to the very outcome they are intended to deliver. What appears as a nursing shortage is exacerbated by practices in allocating nursing. In many cases, actual implementation of "help" not only inhibits the support it intends to deliver, it ironically wastes the precious resources it seeks to save. Numerous examples of this were found.

- Families who would be willing to use the less expensive and more available services of a well-trained home health aide are forced to use more expensive services of a nurse because only nursing service is funded. As one mother stated, "There are times when I do feel he needs a nurse, but not all the time."
- Families who need only a few hours of service a day are forced to use a full day of service or do without any because nursing organizations cannot find a nurse to

work a partial shift. As a mother explained, "Say you only need a nurse two hours this day, four hours that day. An agency is probably not going to be able to do that."

- The system spends precious resources paying for staff to manage paperwork used to deny services for lack of funding.
- After careful scrutiny to assure services are medically necessary, the system has no obligation to assure delivery of the "necessary" service.
- A family who is willing to pay privately for nursing services is prevented from doing so because of agreements signed between the nursing agency and the reimbursing organization.
- When no nurse is available from the primary nursing agency, families are prohibited from using an available nurse from another agency and the primary nursing agency is not obligated to provide back-up even in medically necessary cases.
- While nurses are "unavailable" if paid by agencies (at rates that deducted for administrative costs), the same nurses become available if they receive the rate the agency was paid (inclusive of the administrative costs).
- When nurses are not available from the agency the family elected to use based on its assurance it could fill the shifts, the family is prevented from going to other agencies because the managed care organization will only bill one agency.
- A child with a life-threatening condition is deemed ineligible for in-home nursing support because he does not have a medical device, while another child receives 16 hours of in-home nursing support a day because he has a feeding tube despite the fact that the parent would be willing to train and use an aide for much of that time. As one parent stated, "Without a trach or without a tube, you won't get nursing."
- While nurses are scarce, children who require nursing levels of care go without any care while children who could safely use a lesser qualification level of care use up the scarce resource.
- Foster families who do not need or want respite are forced to accept mandatory respite or have their children removed from the home.
- Services are not coordinated, so families whose children have complex medical needs may not be informed about services that they are eligible for. One parent described her family's experience:

  No one told us to apply for Medical Assistance. No one said we could have therapists in our home. No one told us about respite. We got referred to early intervention only because our case manager at the insurance agency has a child with Down syndrome. No one at the hospital made the referral. So, to this day, we've always found out about things too late.

With all the recent talk about "self-determination," the system still in many ways acts as a barrier to this. Families and workers who come up with innovative ways to meet their needs in ways that use resources prudently are prevented from doing so by paradoxes and

"Catch-22s" of all kinds. Families have to spend exhaustive amounts of time and resources trying to get support. As one mother put it, "Fighting for stuff takes such an incredible amount of time and energy that it wears me out." Another mother commented, "If they wait til a crisis, it'll be too late."

The history of the development of rules and regulations was intended to protect and safeguard. The ultimate safeguard is that children are able to live with loving, stable families. Unfortunately, system regulations have taken on a paradoxical life of their own. The "safeguards" must be reframed within a permanency context, and revisions must be made so that regulations and their implementation support rather than impede permanency for all children.

4. Compartmentalization of services and categorization of funding mechanisms hampers the intent of family support. Programs and services have been added over the years to the array of support mechanisms. Unfortunately, the result has been described as a "hodge-podge." For families it feels like a game. If you fit the magic criteria you win, if not, you lose. If your child has life-threatening health care needs and mental retardation then you may get help. But a child with exactly the same health care needs without a mental retardation label leaves you without help. While you qualify for 16 hours a day or nursing at age 20, when you turn 21 you are no longer eligible for help although your needs have not changed at all. Proposed regulations to expand personal care assistance service exclude those labeled with cognitive impairments.

What these examples point out is that needs do not determine access to services, rather, compartments drive decisions. The system was described as "extremely categorized and eligibility based," "incredibly fragmented," and having "no structure, no guiding principles" in relation to children and adults with complex medical needs. Permanency does not guide the system of care and does not guide the case manager charged with coordinating the delivery of services. Service "coordination" has become an end in itself as opposed to a vehicle to accomplish permanency goals. In this environment, service coordinators (case managers) understand their job to be providing a list of available program options, eligibility criteria, and application procedures rather than sitting with a family and problem solving with them about how to fit pieces together toward a desirable long-term solution. Service coordination needs to be more than a shopping list. It needs to be guided by a philosophy about the child's best interest. Service coordination also needs to feed back to the system what is needed but not available. If truly guided by permanency philosophy, case managers would be advocating for more recruitment of alternate families and would forgo referrals to vacant facility beds.

The compartments and categories offer no overall view of where the system is at in implementing its belief that children should grow up in families. The fact that there is no tracking system that allows the system to know where children do not live with families suggests the lack of primacy of family life. We measure and track what is important. We use information to shape planning. Despite significant efforts by the Cordero Committee to create an information base to track nonfamily placements, it has proven illusive. If a group with the combined experience and expertise of the Cordero Committee cannot

track this system, how is it that a family or a case manager has a chance at navigating the maze? This is further evidence of the lack of permanency as a guiding principle.

Conclusion

Our visit raised many positive as well as challenging issues. Due to the collaborative efforts of various individuals and organizations, some children with the most severe disabilities are being supported in family and community life, and efforts are being made to address the systems barriers. At the same time, certain "gaps" and "perversities" within the system inhibit or prevent family and community life for others, in particular some of the most vulnerable children with complex health needs. Everyone we met was acutely aware of resource limitations and understood the need to prudently manage them. Everyone we met also had ideas about how to work within limited resources and had contributions to make toward solutions. Some of the priorities, in this regard, seem to be: need for effective tracking of children in nonfamily settings; addressing the pathways that lead to facility placement; developing individualized funding and support mechanisms for those over 21 with complex medical needs, inclusive of those with severe developmental disabilities; and revising rules and regulations so that they encourage rather than discourage flexibility, choice, and control for families, and so that they promote rather than impede permanency.

It is also important to recognize that our visit raised numerous positive examples of individuals and organizations that have put permanency philosophy into practice, successfully enabling some children with the most severe disabilities to live at home. Whenever people described what did work, it was always tied to a personal relationship wherein the parties to the relationship were committed to the simple notion that a child belongs in a family. Whenever people described what did not work, it was always tied to an impersonal or anonymous association wherein the parties were committed to managing paper or compartments or meeting rules or regulations. There seem to be two essential parts to the successful methods. One is a relationship defined by emotional connectedness and personal investment. The second part is a clear vision of the task at hand, to devote all activities to the day-to-day lived relationships of a child and a family. At the heart of each is the phenomenon of relationships. That is not coincidentally the heart of permanency philosophy.

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Postscript

This report reflects our observations, thoughts, and reflections at the time of our site visit. We learned before the report went to print that Stuart moved out of the rehabilitation facility and into a group home. While this has many advantages over the facility, it is not the same as a family, as Stuart had so strongly desired. Even more disturbing, we learned the sad news of the death of Denise. We wanted the report to capture the struggles we witnessed, so we did not change it to reflect Stuart's move or Denise's death. But now, as we reread it, and we expect as others read it, the frustration of our lethargic systems reminds us that our efforts are more pressing than ever. The fact that Stuart's dream slipped away in the midst of such a concerted effort to assist him is a glaring reminder of the urgency of addressing the barriers to this as well as the reasons that children are not able to remain with their families in the first place. Denise's death reminds us of just how precious time is and how our systemic dithering may be eating away at the few months someone has yet to live.

Note: All names used throughout this report are pseudonyms.